SEEING THE UNSEEN: RETHINKING DEMENTIA DIAGNOSIS

People affected by dementia and healthcare staff share their insights

ALZHEIMER'S RESEARCH UK FOR A CURE

CONTENTS

FOREWORD

Dementia is the UK's biggest killer. If nothing changes, one in two of us will be affected – either by caring for a loved one, developing the condition ourselves, or both.

Despite this growing crisis, there is hope. Thanks to decades of research, we have entered a new era in the treatment of dementia. Medicines that can slow the progression of Alzheimer's are now licensed in the UK. And across the globe, more than 180 trials are underway, testing nearly 140 new treatments for Alzheimer's disease. But people can only benefit from these advances if they receive an early, accurate diagnosis.

Right now, there are tens of thousands of people with dementia in the UK living without a formal diagnosis. Many face long, confusing and fragmented journeys through NHS services just to get answers. For too many, this process is emotionally draining, practically difficult and far slower than it should be.

This report brings together the voices of those at the heart of this challenge – people affected by dementia and the healthcare professionals supporting them. Their insights are powerful and often painful. People spoke about long waits that left them "heartbroken," of feeling "scared" and "totally helpless" in a system that should be there to help. Healthcare professionals echoed these concerns, with some describing the current system as "shameful" and "not fit for purpose."

What's clear is that, despite the dedication of NHS staff, the system is not working as it should. It lacks clarity, coordination and compassion. One of the most frequently suggested areas for improvement - from both patients and professionals - was the need for earlier diagnosis. At Alzheimer's Research UK, we agree. That's why we launched Dementia Unseen - our campaign calling for fast, fair and accurate diagnoses for everyone who needs one. A dementia diagnosis should be a right, not a waiting game.

There are clear reasons for optimism. An overwhelming 94% of healthcare professionals told us they want to see improvements to the way people are diagnosed – from shorter waiting times to better post-diagnostic support. People living with dementia are also eager to play their part. Many shared their experiences in the hope it would drive change, and told us they want to get involved in research.
This collective willingness – from those delivering care and those receiving it – is deeply encouraging. With the right support, they can be the driving force behind a future where everyone affected by dementia is seen and heard.

There have been promising signs from the Government too - including renewed backing for the Dame Barbara Windsor Dementia Goals Programme and a new Modern Service Framework for dementia and frailty in this summer's 10-Year Health Plan.

But if we're serious about making change, these commitments must be matched with action. Diagnosis is not just a gateway to treatment - it's clarity, connection and support. It's also the opportunity to take part in medical research that could lead us to a cure. With new treatments and innovative diagnostic tools on the horizon, there has never been a more urgent time to future-proof dementia services.

I'm grateful to everyone who contributed to this report. Your voices will shape our ongoing work as Alzheimer's Research UK campaigns for a system that is ready for what is coming, and that works better for everyone affected by dementia.

Hilary Evans-Newton
Chief Executive,
Alzheimer's Research UK

EXECUTIVE SUMMARY

Dementia is the greatest health challenge of our time. It is the UK's leading cause of death, and by 2040, 1.4 million people are expected to be living with the condition. Yet one in three go undiagnosed - denying them vital support, the chance to plan, and the opportunity to join research that could find a cure.

Across 2024 and 2025, we surveyed more than 500 people affected by dementia and over 160 healthcare professionals to understand the realities of diagnosis - what works, what gets in the way, and what needs to change.

AT A GLANCE: PEOPLE AFFECTED BY DEMENTIA

- One in three (37%) waited over a year before seeking help.
- 67% were immediately referred by their GP; of those who waited, 46% were referred within six months and 36% waited longer.
- After referral, 19% were seen by a specialist within one month, 53% within three months, and 74% within six months.
- 30% received a diagnosis within six months of seeking help, 51% within 12 months, and 74% within two years. One in five (22%) were still waiting more than two years after visiting their GP.

Those who were able to get a diagnosis repeatedly told us how important it was in helping to understand the condition, its symptoms and likely trajectory, and in validating their hugely emotive journeys to that point. They explained how a diagnosis shaped planning and coping strategies, as well as accessing symptomatic medication and the chance to take part in dementia research.

“The wait from first going to a GP to being diagnosed was tedious and worrying as my symptoms were increasing in frequency and severity.” - Person with dementia diagnosis

“My mum is struggling with day-today life, and there is nothing we can do about it. We can't even officially put a name to it. It's devastating watching what is happening with no answers, no support. We desperately need the reassurance of a diagnosis, so at least we know.” - Supporter

“The speed of referral to diagnosis was good in our case, but I put this down to a good relationship with our family doctor and my own background in psychology.” - Supporter

AT A GLANCE: HEALTHCARE PROFESSIONALS

- Less than a third (27%) agreed that current diagnostic pathways are fit for purpose.
- Nine in ten (91%) believe diagnosis is beneficial for patients, with 98% saying it is beneficial for families and caregivers.
- Around a quarter (23%) feel unable to provide patients with the best level of care.
- More than nine in ten (94%) would welcome improvements to the diagnostic pathway.

Clinicians raised systemic issues that chimed with their patients' experiences – from the need to improve GP referrals, to disjointed services and, ultimately, an NHS struggling with rising demand and not enough staff and resources to provide good care.

“There is a postcode lottery of what services are available and how quickly people can access them.” - Healthcare professional

“I am not surprised [to hear patients' experiences], I have been working in this area for 15 years now and continue to see no improvement.” - Healthcare professional

THE CHANGES PEOPLE WANT TO SEE

Our findings underline the urgent need to improve how dementia is diagnosed in the NHS. Based on our respondents' insights, we've outlined five key priorities to build a diagnosis pathway that is efficient, equitable, and supportive for everyone:

1. Earlier, faster and more accurate diagnosis: cognitive assessments, imaging, diagnosis and support should be provided together during a single visit to a "one-stop shop" clinic – reducing fragmentation and speeding up care.

2. Consistent and integrated diagnosis: diagnostic pathways should be standardised across regions, with shared digital patient records. Where appropriate, memory assessments should be provided in the community, via home visits, outreach clinics and virtual consultations.

3. Improved pre- and post-diagnostic support: dedicated support services should sit alongside clinical appointments, to help guide people through the diagnosis process and beyond.

4. Investment in people and infrastructure: the Government and NHS leaders must commit to targeted investment for more staffing, infrastructure and training in dementia services.

5. Improved access to advanced diagnostics: diagnosis is being held back by outdated assessment methods and limited access to technology – services need to be future-proofed and made ready to rollout promising next-generation tests on the way, such as blood tests to detect Alzheimer's disease.

These priority actions give further weight to the recommendations outlined in our recent report Delivering Dementia Diagnosis: A blueprint for the future, which sets out a phased, evidence-based plan to ensure everyone affected by dementia can access a fast, fair and accurate diagnosis.

The two surveys underpinning this report were co-designed by people affected by dementia, healthcare professionals, Alzheimer's Research UK and health research experts, Thiscovery.

INTRODUCTION

A timely, accurate diagnosis of dementia can change lives. But too many people face long waits, uncertainty, or no diagnosis at all.

Only around 65–70% of people with symptoms, like mild cognitive impairment, receive a diagnosis[1]. For many, the wait is between 6 and 12 months[2], and we heard of waits of 2 years or longer in this survey. That leaves nearly one in three without a formal diagnosis. Without a diagnosis, people can't access new treatments, plan for the future, or get the care that makes a difference.

As the UK's leading dementia research charity, we approached healthcare research organisation, Thiscovery, to understand the reality behind the numbers, specifically:

- **What the process of getting or giving a dementia diagnosis is like** – from the point of view of people waiting for a diagnosis, those recently diagnosed, their families, supporters and healthcare professionals.
- **To identify what helps or gets in the way of getting or giving a dementia diagnosis**, and how these factors affect the experiences of people going through the process, as well as those supporting them.
- **To find out what would make the diagnosis experience better**, and how these improvements could realistically be put in place.

This report presents findings from two surveys: one gathered insights from people living with dementia or experiencing symptoms, and their supporters; the other captured perspectives from healthcare professionals involved at different stages of the diagnostic pathway.

Creating the surveys was a collaborative effort involving people affected by dementia, healthcare professionals, Alzheimer's Research UK staff, and Thiscovery. Every question was shaped to be clear, accessible and relevant.

We're using the findings to expose the barriers to diagnosing dementia, and to campaign for change that will lead to improvements for everyone.

WHO DID WE HEAR FROM?

This survey brought together a wide range of people affected by or involved with dementia in different ways. People responding included those living with symptoms or a diagnosis, people who support someone with dementia, and healthcare professionals working across various stages of the diagnostic pathway.

Of the **503 people affected by dementia** who completed the survey:

45

people had a **diagnosis of dementia**, received within the last three years (9%).

273

were supporters of people with symptoms of or a diagnosis of dementia, received within the last three years (54%).

59

people had symptoms they were worried about, but no diagnosis (12%).

126

were people who did not fit into the other three categories, but wanted to give their views. Of these, 58 provided free-text comments on their experience or interest in the project; 33 were supporters, and 15 had a diagnosis or worrying symptoms (25%).

> Throughout this report, we use the term ‘supporter’ to describe people supporting or caring for people with worrying symptoms or a diagnosis of dementia. This reflects the preferred terminology of those affected by dementia who co-designed the survey.

We gathered views and experiences from **161 healthcare professionals** working across dementia diagnosis pathways, of whom **148 gave complete information about their professional role**, comprising:

64

nurses, specialist nurses or nurse practitioners (43%).

15

occupational therapists (10%).

18

old age psychiatrists (12%).

34

other healthcare professionals (19%), including general practitioners (GPs), geriatricians, neurologists, physiotherapists, and professionals in management, support services, and commissioning roles.

17

psychologists (12%).

ABOUT THE RESPONDENTS

People affected by dementia

Most people (90%) who reported symptoms or a dementia diagnosis were aged over 60.

Most people (84%) with symptoms or a dementia diagnosis chose to complete the survey without support from someone else.

Among the 16 who said they wanted support, just over half (9 people) decided to provide joint answers.

Two-thirds of all people responding were female (66%).

Supporters of people with symptoms or a diagnosis were mainly over 50 (86%), with 50–59 the most frequently selected age group (27%).

Among supporters who felt comfortable sharing this information, 28% said the person they supported had since passed away.

Most supporters (85%) said that the person they support or had supported had a diagnosis of dementia.

Most people reported their ethnic group to be White (94%).

Healthcare professionals

Healthcare professionals who took part worked across the diagnostic pathway:

60% involved in specialist care (such as memory clinics),

35% in community-based care,

21% in secondary care settings,

15% in primary care.

Of healthcare professionals responding:

Most had substantial experience in their roles with 54% reporting more than 10 years' experience and 22% reporting between five and 10 years' experience.

Most respondents were female (82%).

Across all healthcare professionals responding, 87% reported their ethnic group to be White.

The majority of respondents were aged between 40 and 59 years (63%), with 50–59 being the most frequently selected age group (34%).

Geographically, responses came from across England, with the strongest representation from the East of England (22%) and South West (21%), followed by London (19%) and the North East and Yorkshire (17%).

HOW DID WE HEAR FROM THEM?

People were invited to complete the surveys on the secure online Thiscovery platform (thiscovery.org). The surveys used a mix of closed but predominantly open questions to gather reflections from people about their experiences of dementia diagnosis pathways.

WHAT WE ASKED PEOPLE AFFECTED BY DEMENTIA

Based on people's experience of dementia, we developed tailored questionnaire routes for the following four groups:

- people given a diagnosis of dementia within the last three years,
- people with symptoms they were worried about but no diagnosis,
- supporters of people with symptoms of or a diagnosis of dementia within the last three years, and
- people who did not feel they fitted into the other three categories but who wanted to share their views.

Questions covered their experiences of symptoms, of seeking answers and a diagnosis, views on the value of diagnosis, and suggested improvements to services. Questions were developed and tested with members of our Lived Experience Involvement Group.

The survey was live from 30 October 2024 until 19 December 2024. It was promoted through existing networks, contacts and social media of Alzheimer's Research UK and Thiscovery, also with other dementia organisations for onwards sharing.

WHAT WE ASKED HEALTHCARE PROFESSIONALS

Healthcare professionals were asked about their experiences of current diagnostic processes and their views on how these could be improved. They also reflected on comments from people affected by dementia, gathered through the separate survey.

The survey was live from 14 April 2025 until 2 June 2025. It was promoted through existing networks, contacts and social media of Alzheimer's Research UK and Thiscovery, also with clinical and healthcare professional networks for onwards sharing.

Response rates in both surveys varied by question, as questions were not compulsory. All percentages are calculated based on the number responding to each specific question.

All the survey questions are included in supplementary materials.

Due to the purposive and self-selecting sampling approach used within this project, it is not possible to generalise the findings to the whole population. The views and experiences expressed in this report may differ from others who did not hear about or respond to these surveys.

PEOPLE'S EXPERIENCES OF SYMPTOMS

People living with symptoms of dementia described a gradual and often confusing journey. For most (62%), their symptoms had been present for more than two years before help was sought.

They spoke of noticing **subtle changes in their memory and thinking,** misplacing items, forgetting names, or asking the same questions repeatedly. Words sometimes failed them, and processing information became more difficult. Everyday tasks such as driving began to feel unfamiliar or overwhelming. People also reported brain fog and struggling with decision-making.

These cognitive challenges were often accompanied by moments of disorientation and confusion.

Many **grappled with the uncertainty** of what was happening to them. People described feelings of panic, frustration and isolation.

Concerns about the future were often accompanied by a growing fear of becoming a burden to others. Losing the ability to work, drive or manage daily routines contributed to a **deep sense of vulnerability and loss of independence.**

> **“I feel frustrated, loss of control over my life and guilt/fear of becoming a burden to my family, the community and the system.”**
> **- Person seeking dementia diagnosis**

Relationships with healthcare professionals are also affected. People reported feelings of frustration, even anger, toward the systems and professionals involved in their care.

> **“Felt angry and frustrated by health system and their processes in assessment along with consultants not agreeing on a diagnosis.”**
> **- Person seeking dementia diagnosis**

SUPPORTERS' VIEWS ON WITNESSING SYMPTOMS

Supporters highlighted how memory problems led to **challenges with activities of daily living**, like dressing, cooking, driving, phone calls, general decision-making and managing finances. They described their loved ones as **exhibiting denial** or having **a lack of awareness of their own cognitive decline** – possibly as a way of coping with the changes.

> **“My father accepted their diagnosis without question, my mother denied hers, and still does 18 months later, blaming all issues on my father. Her denial/blame is the hardest emotionally.” - Supporter**

This, in turn, added complexity to their own emotional experience. As symptoms progressed, supporters described shifting through a range of emotions, from sadness and despair to anger and a sense of loss. Feelings of powerlessness were also expressed in response to witnessing the cognitive and behavioural decline of a loved one.

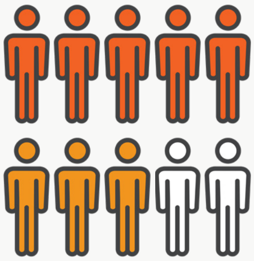
The journey through dementia – both for individuals and their supporters – is marked by a profound sense of grief.

> **“Heartbroken, scared, helpless, alone, defeated, angry.” - Supporter**

ASSESSMENT AND THE CURRENT DIAGNOSIS PATHWAY

PEOPLE’S EXPERIENCES OF BEING ASSESSED

People reported a wide range of wait times for their initial appointment, typically with a GP.



Just over **half of people (54%) saw their GP within a month**, but **nearly a third (30%) waited over a month** before they saw their GP.

16% of people weren’t sure how long they’d waited.

Supporters told us that people with symptoms underwent multiple tests and assessments at their initial GP appointment, including memory tests, thinking tests, blood tests, ECGs and blood pressure tests. However, **onward referrals were not straightforward, with supporters highlighting some GPs’ hesitance to refer and long wait times to see a specialist.**

> **“Told the wait would be over a year.”** **- Supporter**

> **“First appointments were a struggle as no provider wanted to refer him to a specialist service or a neurologist.”** **- Supporter**

Two-thirds (67%) of people said that their GP agreed to an **immediate referral for specialist assessment.**

Of those that had to wait, the time taken for the GP to agree to a referral varied, with 46% being referred within six months and **35% taking longer than six months.**

Some **healthcare professionals** suggested there were problems with initial recognition and referral in primary care:

> **“Memory Clinics are clogged up with referrals from GPs for younger adults with mild memory concerns who obviously don’t have dementia.”** - Healthcare professional

> **“Poor GP referral quality (memory issues mentioned but no pre-screening assessments).”** - Healthcare professional

THE REFERRAL TO A SPECIALIST

Once the referral had been made, 19% of supporters said that the person they care for was seen by a specialist within a month. By three months, 53% said they had been seen, and by six months, 74% had been seen.

Some people (15%) waited between six months and two years to be seen by a specialist, with 11% not sure how long the wait was.

People described a **complex and ongoing journey through the assessment process** with a specialist. This often involved a series of appointments, tests, and referrals spanning weeks or even months. Some shared experiences of follow-up appointments scheduled as far as a year ahead, while others spoke of **long waits for further assessments** with different specialists, such as neurologists or psychiatrists.

Assessments typically involved a combination of tests, including memory tests, thinking tests, and clock-reading exercises, conducted in person, over video calls, or through a combination of methods, depending on the circumstances.

> **“The dementia nurse started by having what felt like quite a general conversation with my Dad, also involving my Mum and me, but during which she would have been assessing his answers so asking about his childhood, school, career, what he enjoys doing etc before asking about things that are more clearly linked to dementia such as executive function tasks, whether he has hallucinations, forgets things etc. After that she asked Dad to perform more formal memory tests (e.g. naming animals beginning with a certain letter, drawing a clockface) - my Mum and I were invited to leave the room at this point.”** **- Supporter**

Some people described how the assessment process was tailored to the individual’s needs. For example, one person mentioned that the tests were “verbal questions and answers”, rather than pen-and-paper tests, due to the individual’s physical needs. However, several people felt that healthcare staff were not always aware or accommodating of these needs.

> **“No allowance was given, for example, to allow my Dad to be reminded to put his glasses on to read material.”** **- Supporter**

Alongside cognitive tests, CT and MRI scans were commonly used to gather information about brain structure and function and provide insights into the underlying causes of cognitive impairment. These scans were often described in negative terms.

> **“...the scan did not go well. The wife did not like the machine, and it took a nurse and myself to get her on the bed and relax; she was under the impression that they were going to take a slice of her brain to look at.”** **- Supporter**

The assessment process could have a strong emotional impact on both patients and their supporters. Several people described the experience as “stressful” and “frustrating”, particularly when communication barriers or other challenges arose.

> **“...the test was very stressful for my Dad due to the approach taken, and my Mum, who does not have dementia, struggled with some of the questions. It was a difficult experience for them both.”** **- Supporter**

A POSITIVE PATHWAY TO SUPPORT

People also described **some positive experiences** related to assessment, which often involved a **supportive GP who facilitated a quick referral to a memory clinic**, where they received comprehensive testing and support from healthcare professionals like nurses and consultants. Timely access to medication and community-based services were also highlighted as important factors in their journey.

“Since we have had our GP on board with our situation, our diagnostic journey has all been positive with a quick and caring pathway to our memory clinic referral for tests and consultation, followed by referral for brain scans and results, then onto discussions and medication. We were followed up for approx. 15 months after medication started and are now back under the care of our GP.” - Supporter

Having a strong relationship and maintaining continuity of care with the GP also aided the diagnostic process, for example, through quicker symptom recognition and referral.

“The speed of referral to diagnosis was good in our case, but I put this down to a good relationship with our family doctor and my own background in psychology, that she trusted my instinct and judgement and made an emergency referral. Our GP knew Mum’s history very well. So the continuity of care was really beneficial.” - Supporter

PEOPLE’S EXPERIENCES OF RECEIVING A DIAGNOSIS

Those who described a gradual decline in cognitive function received diagnoses of “mild cognitive impairment” or “minor cognitive impairment”. These later progressed into more severe conditions, such as “dementia” or “Alzheimer’s”. In some cases, “small vessel disease” or “vascular impairment” were described as contributing factors.

Overall, when asked how long supporters thought it took to get a diagnosis:

Just **over half of people (51%) received a diagnosis within a year** of first seeking help, but nearly **23% waited one to two years** and **22% waited over two years** to be diagnosed.

5% of people weren’t sure how long it had taken.

However, the primary focus of their reflections was on the challenging and negative experiences of the dementia diagnosis pathway. Supporters described widespread difficulties with:

- obtaining a clear and prompt diagnosis,
- navigating the system,
- post-diagnosis support, and
- severe and damaging impacts (particularly emotional impacts) of the diagnosis process.

DELAYS, MISDIAGNOSIS AND AN UNCERTAIN DIAGNOSIS

For many supporters of people living with dementia, **the journey to a clear diagnosis was far from straightforward.** Some described how their loved ones were first misdiagnosed, faced long waits before receiving an accurate assessment, or were left with an incomplete or uncertain diagnosis.

“There are no answers. We are waiting over a year now and still no confirmation of a dementia (diagnosis). My mum is struggling with day-to-day life, and there is nothing we can do about it. We can’t even officially put a name to it. It’s devastating watching what is happening with no answers, no support. We desperately need the reassurance of a diagnosis, so at least we know. This wait is harmful and distressing.” - Supporter

“The wait from first going to a GP to being diagnosed was tedious and worrying as my symptoms were increasing in frequency and severity.” - Person diagnosed with dementia

In some cases, healthcare professionals offered conflicting opinions. This inconsistency caused confusion and left families feeling uncertain and unsupported.

“One consultant psychiatrist who only reviewed medical notes and assessments and met me once stated he believes I have a functional neurological disorder, while a consultant psychiatrist from adult services who has been heavily involved in my care, along with his community mental health team, including his occupational therapist, believed I have dementia.” - Person seeking dementia diagnosis

Critically, there were some who believed that delays or missed diagnoses had contributed to a faster progression of the disease.

“Had he been diagnosed with early symptoms in 2017, then the medication may have been effective in slowing the deterioration.” - Supporter

HEALTHCARE PROFESSIONALS ECHOED THE CHALLENGES

Only 27% of the healthcare professionals we surveyed agreed that current diagnostic pathways are fit for purpose.

They consistently highlighted a **lack of funding and staff**, describing services as “under-resourced/funded”, with “not enough staff to run clinics due to a massive rise in referrals”. Many warned that “demand hugely outstrips capacity”, and noted that the growing ageing population was adding yet more pressure to an **already overstretched system.**

“...by the time a person has waited 40 weeks their memory has declined further and they have not had the appropriate support and advice in that time.” - Healthcare professional

“...not enough staff to run clinics due to massive rise in referrals” - Healthcare professional

“Services need to consider new innovative ways of working to manage demand and not rely on old models of working.” - Healthcare professional

“There is a postcode lottery of what services are available and how quickly people can access them.” - Healthcare professional

Healthcare professionals raised concerns about the diagnostic journey for people with young-onset dementia (YOD). The current approach too often reflects an inequitable healthcare system – one that treats symptoms rather than seeing the person behind them.

Dementia can affect people in profoundly different ways depending on their stage of life. Younger people often face significantly longer waits for a diagnosis, and are more likely to be misdiagnosed.

> **“For people and families living with YOD, the pathways are broken or non-existent, and they get little to no post-diagnostic support; the help is often for 65+ and is siloed.”**
> **- Healthcare professional**

CHALLENGES IN NAVIGATING THE HEALTHCARE SYSTEM

People with symptoms and their supporters experienced **frustration and uncertainty** navigating the healthcare system in search of a clear diagnosis or **support following a diagnosis.** A lack of coordination and clear communication within the healthcare system compounded this.

Supporters described needing to work hard to ensure their loved one got the investigations and assessments they felt they should.

> **“The fact that I have had to chase everything at every stage. Everything has been driven by me and I have needed to push all those involved to just do what I would consider to be their job.” - Supporter**

Healthcare professionals cited that fragmented care, where services are not linked up, makes navigating the care system even more complex.

> **“The trajectory of the condition is fragmented with families bouncing around the system depending upon whether their needs are perceived as ‘health’ or ‘social’.”**
> **- Healthcare professional**

> **“A more integrated MDT [multidisciplinary team] approach would be beneficial.”**
> **- Healthcare professional**

THE EMOTIONAL IMPACT OF THE DIAGNOSTIC PROCESS

Supporters experienced a range of emotional responses to the diagnostic process, including a sense of being let down by the healthcare system. One person described feeling “angry and frustrated with the process”, while another expressed their “disappointment” with the diagnostic process.

The emotional impact of the diagnostic process was substantial for many supporters, notably in needing to be present for what could be highly upsetting assessments.

> **“The meeting at the memory clinic was emotionally difficult for all of us. Seeing my dad unable to describe his path from primary school to secondary school, then university, and unable to describe the job he once loved, was difficult, particularly as, before becoming unwell, he had a brilliant mind...” - Supporter**

> **“I was present when my wife did the written and oral tests. That was emotionally difficult for me to see her struggling.” - Supporter**

The lack of clear and timely diagnoses, as well as the perceived mishandling of cases, led to a sense of mistrust, exasperation and a desire for a more compassionate and effective approach to dementia care.

> **“I would say I am just living with gradual, worsening symptoms and not seeking any further answers, as I feel no one will take me seriously. I feel I am a sitting duck waiting for symptoms to get worse before I’m brave enough to go back to the doctors.” - Person seeking dementia diagnosis**

INADEQUATE POST-DIAGNOSIS SUPPORT

Supporters of people with dementia described a **lack of post-diagnosis support and information** for individuals and their families after a dementia diagnosis, leaving them feeling **isolated and unprepared to manage the challenges ahead.**

> **“The worst thing about the diagnosis was that there was no immediate support or advice. Although I expected my partner had dementia, it still came as a shock to realise that our life in future would be very different and I had no idea how I would cope.” - Supporter**

Many people expressed frustration at the lack of information, resources, and practical guidance provided to them, leaving them to navigate the dementia journey on their own. They described feeling abandoned, unsupported and “left to cope with it” alone, with limited guidance on available resources and follow-up care.

> **“It felt like a whirlwind – leaflets, books, people calling me on behalf of mum. And then it felt very much like you were on your own unless you sought help or advice.” - Supporter**

Healthcare professionals also expressed their concern about the lack of post-diagnostic support for people.

> **“I feel we offer good pre-diagnostic support, but I worry about how little post-diagnostic support can be offered. We have to discharge after a diagnosis is delivered and treatment started.” - Healthcare professional**

POSITIVE EXPERIENCES OF THE DIAGNOSTIC PROCESS

Some supporters and people with a diagnosis or symptoms had more positive experiences and described medical professionals who offered genuine care and support. They valued staff who listened attentively, showed empathy, and worked alongside them as partners in their care. Memorable examples included doctors who took time to understand their history, explored concerns in depth, and tailored treatment and support to their individual needs.

For many, building a strong, trusting relationship with medical staff made it easier to face the challenges of their condition and find the help they needed.

> **“My GP practice has been supportive and also commented on different opinions within psychiatry letters sent to the GP. GP has a genuine understanding relating to my frustration that has impacted on me receiving my NHS pension due to a confirmed diagnosis.”** - Person seeking dementia diagnosis

There were positive experiences from healthcare professionals, too, that highlighted good practice.

- **Strength of teams and services** – healthcare professionals praised the quality of their multidisciplinary teams, clear diagnostic pathways, and commitment to best practice. Some services provide end-to-end dementia care, supporting both patients and supporters throughout their journey.

  > **“We have a dedicated dementia service that goes from diagnosis to post-diagnostic care, and we are able to support both people with dementia and their carers for the whole of their journey.”** - Healthcare professional

  > **“We have clear diagnostic pathways in our Memory Assessment Service and MCI pathway. I work alongside compassionate and dedicated colleagues in a multidisciplinary team. We are MSNAP [Memory Service National Accreditation Programme] accredited so regularly monitor how we compare to best practice guidance/standards.”** - Healthcare professional

- **Clinical confidence and autonomy** – many felt assured in their competence and motivated by working in patients’ best interests. Some valued the high level of autonomy they have in following service pathways.

  > **“I am confident that I am working competently with the patient’s best interests at heart.”** - Healthcare professional

- **Reducing delays** – initiatives such as referring people directly to multidisciplinary co-diagnosis meetings have successfully reduced waiting times for assessment and diagnosis.

  > **“I have the ability to refer patients to an MDT [multidisciplinary team] meeting for Dementia Co-Diagnosis, which sees reduced waiting times for assessment and diagnosis.”** - Healthcare professional

THE VALUE OF A DEMENTIA DIAGNOSIS

After months or even years of uncertainty, receiving a dementia diagnosis is a pivotal moment.

For people with dementia and their supporters, a diagnosis can **validate their concerns, open the door to support, and help them plan for the future.** For healthcare professionals, giving a clear diagnosis means they can guide people towards the right care and resources from the very start.

But, as this research shows, people's experiences are mixed, with some feeling let down by overstretched and fragmented healthcare services.

90% of healthcare professionals agreed or strongly agreed that diagnosis is beneficial for patients, while 98% agreed or strongly agreed that it is beneficial for families and caregivers.

94% of healthcare professionals agreed or strongly agreed that they would welcome improvements to the diagnostic pathway.

COMING TO TERMS WITH THE CONDITION AND GAINING CLARITY

An early diagnosis was invaluable in helping individuals and their supporters to understand the condition, its symptoms, and its likely trajectory.

The ability to put a "name to it" and have a clear understanding of the condition was seen as crucial for managing the situation effectively.

“ **I would like to know what is happening and what might happen over the next few years."** - Person seeking dementia diagnosis

“ **In order to understand what is happening to me."** - Person with dementia diagnosis

“ **Can be a relief to know that what's happening is caused by an illness, rather than the person."** - Supporter

“ **Hugely important. My relative knew there was something wrong and found it quite validating to have this confirmed, despite friends/family/GP initially saying there wasn't anything wrong."** - Supporter

For supporters, gaining insight into the changes in their loved one's behaviour also helped with their own feelings about the situation.

“ **Oh yes, a diagnosis is very important. Trying to cope with the changes in my husband was extremely difficult. Dealing with repetition, denial, lies, confusion and so much more without a diagnosis, I would have been driven mad and no help!"** - Supporter

ACCESS TO RESOURCES, TREATMENT AND SUPPORT

For many, getting a diagnosis facilitated access to important resources, treatments, and support services that could significantly improve quality of life.

“ **[a diagnosis can] prepare not only yourself but the family, the community and you can look out for coping strategies to manage the condition."** - Person seeking dementia diagnosis

Another highlighted that a diagnosis allows for "the opportunity for medical intervention" and the chance to "participate in trials" that could slow the progression of symptoms. As one supporter noted:

“ **[my relative] now has medication to manage the symptoms and is connected with support relating to dementia."** - Supporter

The prospect of slowing disease progression and maintaining quality of life was a key driver of this positive sentiment.

“To know what it is, get treatment and help, and get on with living.” - Person with dementia diagnosis

“It is important to get the earliest diagnosis so that treatment can start. I know there is no cure, but the person’s quality of life can be optimised.” - Supporter

THE GAPS IN CARE FOLLOWING A DIAGNOSIS

A diagnosis does not always offer a route to additional support, as some people reflected:

“The diagnosis has allowed time to think about future care needs. It has not resulted in any support.” - Supporter

“Whilst the neurologist carefully took me through the evidence and scans, there was no information about support at all.” - Person with dementia diagnosis

The nature of diagnoses also meant that people with dementia did not necessarily receive the support their families were hoping for.

“The diagnosis caused so many issues when trying to get support. The term mild cognitive impairment was wrong based on the testing and severity of symptoms but as a result social services wanted to send him home where he was not safe and was neglecting himself. It was a stressful time and emotionally draining. Dad had been in for an extended drain at a hospital and they couldn’t get carers. He was sent home with one, immediately fell and I had to trick him into going to a care home. So hard and so distressing.” - Supporter

Healthcare professionals also highlighted the critical gap in post-diagnostic care:

“...after a diagnosis, an individual has the option of attending an information meeting and that is it... for most people they are left to come to terms with the diagnosis alone.” - Healthcare professional

Sadly, when asked about providing care required only 43% of healthcare professionals agreed they were able to; 23% disagreed, and 34% remained neutral.

STIGMA AND NEGATIVITY SURROUNDING A DIAGNOSIS OF DEMENTIA

While most people expressed relief and validation at having a clear understanding of their loved one’s condition, a few did note the “negative connotations”, and “stigma” associated with a diagnosis.

“For me I want to know what I might be dealing with but at the same time I would dread a diagnosis of dementia” - Person seeking dementia diagnosis

“Ultimately, Mum getting a diagnosis hasn’t really helped her but has made her upset at knowing she has it. Other than eventual access to services it’s been a negative for her. I wish my family had known this first.” - Supporter

“Society needs to be educated to remove the stigma surrounding dementia, as has happened over recent years with cancer. The big D has replaced the big C as the bogeyman.” - Supporter

RESPONSES TO THE LIVED EXPERIENCE OF SEEKING AND GETTING A DIAGNOSIS

To explore healthcare professionals' views on lived experiences of the current system (identified through our previous survey of 500 people with symptoms or a diagnosis of dementia), we presented three key topics identified as major pain points, along with relevant quotes from people:

1. The long, emotionally exhausting diagnostic journey

2. Challenging assessment processes, not tailored to the individual

3. A lack of coordination and communication

Healthcare professionals were asked: **"What three words would best describe your reaction to the insights shared above?"**

Their responses were frequently highly emotionally charged. We reviewed and categorised these responses into five topic areas:

THE OVERWHELMING EMOTIONAL IMPACT

sad exhaustion upset distressing
emotional sadness despair
disheartened heartbreaking sorrow

The most common responses reflected deep sadness and distress. Many healthcare professionals expressed feeling emotionally affected by the experiences shared.

FRUSTRATION WITH SYSTEMIC FAILURES

disappointing angry not fit for purpose
appalling irritated shameful
shocking frustrated broken failed

Anger and frustration were equally prominent, with some using stronger language, describing the system as broken and "not fit for purpose."

RECOGNITION, NOT SURPRISE

not surprised familiar usual
typical unsurprising expected

A number of healthcare professionals expressed familiarity with these problems. In responses which were slightly longer, we heard "unfortunately it's the fact most cases" and "I am not surprised, I have been working in this area for 15 years now and continue to see no improvement."

EMPATHY AND SOLIDARITY

sympathy empathy relatable
recognition understanding

Many responses showed deep empathy. Healthcare professionals identified with both patients and colleagues, showing "solidarity" with the struggles described.

MOTIVATION FOR CHANGE

determined to do better motivated
investment + proactive = value
change needed

Despite the negativity, some professionals expressed determination around the need for change.

DRIVERS OF CHALLENGES IN THE SYSTEM

When asked what might be driving the issues experienced by people with dementia and their supporters, **healthcare professionals identified understaffing and lack of resources** as the most common cause of difficulties for people on the dementia diagnosis pathway – and this included all staff, not just those who are clinically trained.

“Likely insufficient admin staff (memory clinic takes significant skilled admin staff for it to run smoothly, but this is often overlooked). Would we tolerate this if it was a cardiology service? Older adult and psychiatry services are not sexy and not prioritised in the same way.” **- Healthcare professional**

Healthcare professionals additionally identified challenges with **coordination and communication** (for example, understanding how to navigate the system), the diagnosis process (including long waiting times), and lack of post-diagnosis support (Figure 1).

“One of the biggest issues is the lack of seamless communication between health and social care services. People often fall through the cracks between GP practices, memory clinics, social services, and domiciliary care providers. This leads to delays in diagnosis, inconsistent care, and confusion for families who are left trying to coordinate everything on their own.” **- Healthcare professional**

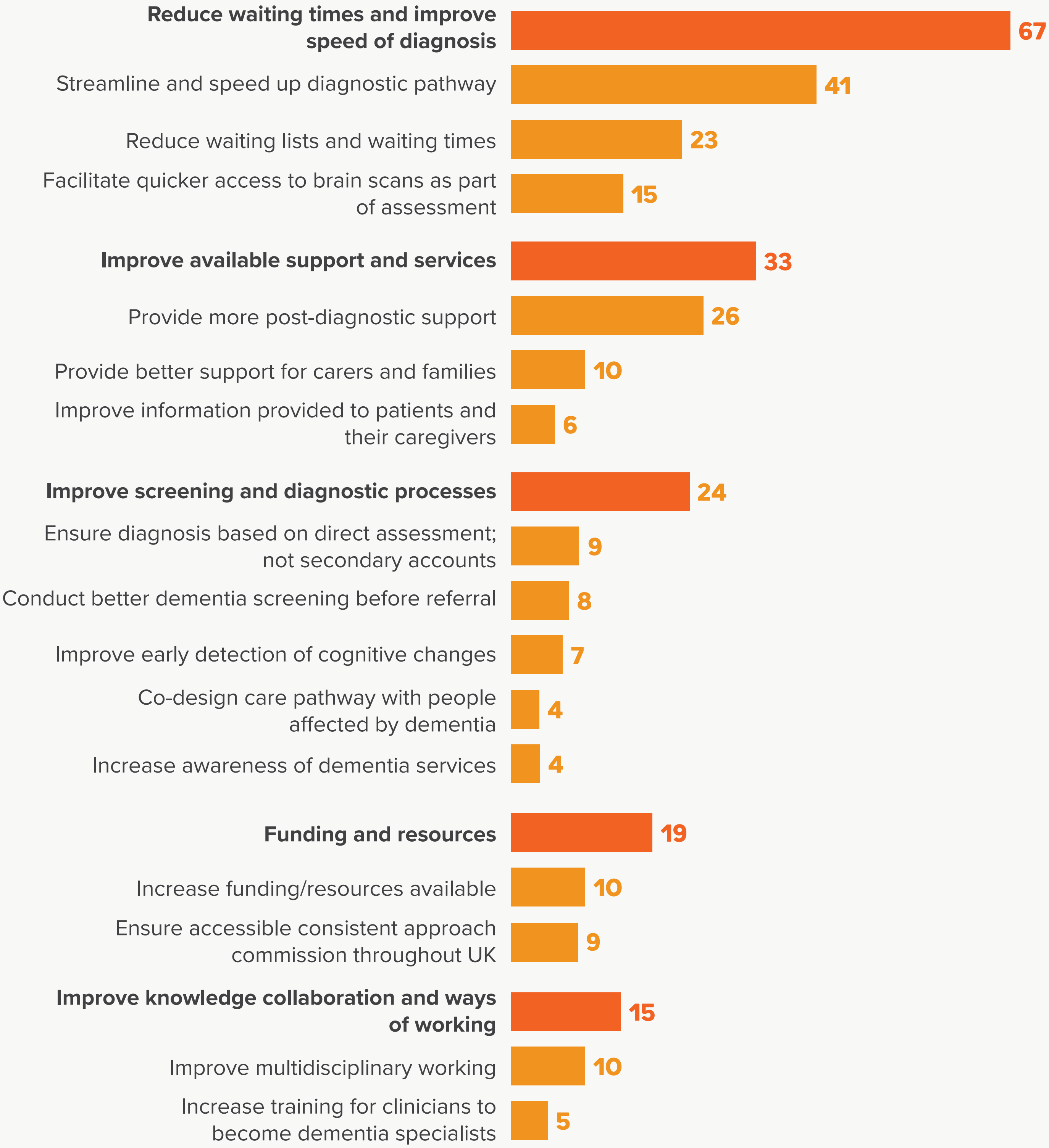
“Too many delays in the system. I find it infuriating someone has to see the dementia nurse first, then wait for the MDT [multidisciplinary team] where they discuss it with one of us (and none of the consultants have paid time to attend the MDT). Then because we haven’t actually seen the patient it feels like we have to either cobble together a diagnosis or ask them to attend a medic’s clinic so we can see them, or ask for further neuropsych (with a huge waiting list).” **- Healthcare professional**

Figure 1. Coding framework for free-text responses to the question **"From your perspective, what do you think is causing some of the issues that people with dementia and their supporters have described?"**

Orange bars show main themes; mandarin bars show specific topics within each theme. Each response was analysed for all themes mentioned. A single comment discussing both 'lack of staff' and 'increasing demand' would be counted in both categories, which is why sub-theme numbers don't always add up to main theme totals.

Figure 2. Coding framework for free-text responses to the question **"If you could fix one thing about the diagnostic pathway for dementia, what would it be and why?"**

Orange bars show main themes; mandarin bars show specific topics within each theme. Each response was analysed for all themes mentioned. A single comment discussing both 'lack of staff' and 'increasing demand' would be counted in both categories, which is why sub-theme numbers don't always add up to main theme totals.



CHANGES PEOPLE WANT TO SEE

This research highlights the urgent need for a more efficient, equitable, and supportive pathway for diagnosing dementia in the UK. People affected by dementia and healthcare professionals consistently describe a **system that is too slow, fragmented, and difficult to navigate**—leaving individuals without timely answers or adequate support.

From these insights, we've identified five priority areas for change:

1. EARLIER, FASTER AND MORE ACCURATE DIAGNOSIS

Waiting for answers while symptoms worsen is unacceptable. People described delays of over a year for specialist appointments, despite dementia being a progressive and life-limiting condition.

“...how can you leave someone waiting over a year for a clinic for what is a terminal illness?” - Supporter

“It is important to get the earliest diagnosis so that treatment can start. I know there is no cure, but the person's quality of life can be optimised.” - Healthcare professional

Healthcare professionals proposed a “one-stop shop” clinic model that consolidates cognitive assessments, imaging, diagnosis, and initial support into a single visit—reducing fragmentation and speeding up access to care.

“One-stop shop clinics. Cognitive assessment, scanning and diagnostic evaluation all at one appointment, followed by rapid prescribing of [symptomatic treatments] and follow-up.” - Healthcare professional

2. CONSISTENT AND INTEGRATED DIAGNOSIS

There was strong consensus that everyone across the UK should have access to the same high standard of dementia diagnosis and support. Yet, people often experience a fragmented system with poor communication between services.

“So many people are fobbed off and ignored and have to push to be listened to.” - Supporter

“To be given clear, simple, and comprehensive answers. At the moment, I don't know what happens next, will I be seen again?” - Person seeking dementia diagnosis

Healthcare professionals suggested standardising diagnostic pathways across regions and introducing shared digital records would improve transparency, reduce duplication, and ensure continuity of care.

Bringing memory assessments into community settings – via home visits, outreach clinics, or virtual consultations – would also make services more accessible.

“One of the biggest issues is the lack of seamless communication between health and social care services. People often fall through the cracks. ...This leads to delays in diagnosis, inconsistent care, and confusion for families who are left trying to coordinate everything on their own.” - Healthcare professional

“Bringing memory assessments into the community... would reduce delays and make the process more accessible, particularly for housebound or anxious individuals.” - Healthcare professional

3. IMPROVED PRE- AND POST-DIAGNOSTIC SUPPORT

The research shows that too often, people are struggling to navigate a healthcare system that is confusing and complex. Despite the hard work of dedicated healthcare professionals, many people feel abandoned after receiving a diagnosis, with little to no practical support offered.

“It shouldn’t be the end of the process so much as the start of a process of care and support.” - Person with a dementia diagnosis

Healthcare professionals want better support for patients and their supporters to guide individuals through the diagnostic process and provide emotional and practical support.

“Like Scotland, set up a service... that allows people/families to receive a year of post-diagnosis support.” - Healthcare professional

“A support service that sits alongside the diagnostic process. ...Make sure people are supported and ‘held’ through the process.” - Healthcare professional

4. INVESTMENT IN PEOPLE AND INFRASTRUCTURE

Healthcare professionals are working in an overstretched system, citing underfunding, workforce shortages, and inadequate training as major barriers to timely diagnosis and care.

There is a clear call from professionals for government and system leaders to prioritise dementia diagnosis and allocate appropriate funding to support it. Without targeted investment in staffing, infrastructure, and training, services will continue to struggle to meet growing demand.

“Integrated Care Boards need to start funding these services appropriately. Adequate staffing to meet demand.” - Healthcare professional

“GPs need more training on the referrals to MAS [Memory Assessment Service] as we often take time rejecting referrals due to inadequate information.” - Healthcare professional

5. IMPROVED ACCESS TO ADVANCED DIAGNOSTICS

Despite the emergence of promising diagnostic tools – such as blood-based biomarkers and genetic testing – many NHS services lack the infrastructure and capacity to implement them. Healthcare professionals highlighted that limited access to MRI scans, poor reporting quality, and outdated diagnostic methods are holding back progress.

“...We should be planning ahead for [blood-based biomarkers] as well as [genetic] testing. ...We are missing huge opportunities to recruit patients into research studies and biobanks.” - Healthcare professional

These insights and the changes people want to see add further support to the recommendations outlined in our report **Delivering Dementia Diagnosis: A blueprint for the future**[3]. Our blueprint outlines a bold, evidence-based plan to ensure everyone affected by dementia can access a fast, fair and accurate diagnosis - empowering people to access support, join research and benefit from new treatments.

BLUEPRINT FOR DEMENTIA DIAGNOSIS

1. SET NATIONAL STANDARDS

NHS England and the Department of Health and Social Care: collaborate with professional bodies, dementia charities and people with lived experience to identify and set out requirements for the workforce and skill mix needed for dementia diagnosis services.

National Institute for Health and Care Excellence: develop guidelines for mild cognitive impairment to ensure early identification and consistent follow-up.

NHS England and the Department of Health and Social Care: align waiting time targets for dementia diagnosis with other conditions.

2. ENABLE DELIVERY

NHS England and the Department of Health and Social Care: ensure Integrated Care Systems have clear and consistent pathways for access to clinical expertise and diagnostic tests.

NHS England and the Department of Health and Social Care: set out projected demand for clinical expertise and diagnostic tools in strategic plans and match this with necessary investment.

Local health systems: ensure dementia diagnosis services have appropriately resourced multidisciplinary teams and necessary training to adapt to new developments.

3. UNLOCK INNOVATION

Government: commission the National Institute for Health and Care Excellence and the Medicine and Healthcare Products Regulatory Agency to put in place a new streamlined pathway for dementia diagnostics.

Government: support new technologies to enhance productivity, like AI review of scans and ultra-fast MRI.

Integrated Care Boards: develop a strategy for introducing new diagnostics, drawing on NHS England and the Department of Health and Social Care's demand assessments.

4. HARNESS DATA

NHS England and the Department of Health and Social Care: invest in additional capacity at a national level to work with local health systems to embed routine data collection and publication, including dementia type, progression stage and waiting times.

NHS England and the Department of Health and Social Care: develop a public dementia data dashboard for transparency and accountability.

NHS England and the Department of Health and Social Care: ensure data from new innovations is captured to inform practice, planning, and research, including via the forthcoming Health Data Research Service.

GLOSSARY

ACIs – acetylcholinesterase inhibitors, the class of drugs prescribed to people with Alzheimer's disease, which include donepezil, rivastigmine and galantamine.

MAS – Memory Assessment Service

MCI – mild cognitive impairment

MDT – multidisciplinary team

MSNAP – Memory Services National Accreditation Programme

Pathway – a term used to describe a patient's journey through the healthcare system.

Supporter – someone who supports or cares for a person with dementia symptoms or a diagnosis.

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This project was carried out in partnership with Thiscovery on behalf of Alzheimer's Research UK.

Thiscovery supports innovation and improvement in health and care by unlocking the knowledge and experience of patients, staff and the public. Our expert team and digital platform use advanced qualitative research methods to engage diverse participants and deliver robust insight that helps organisations solve real problems with evidence-based solutions.

We'd like to thank the team at Thiscovery for their commitment, enthusiasm and expert advice. This was an enjoyable project to work on and we're grateful to Thiscovery for the opportunity to learn and develop this survey with them and our lived experience volunteers.

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